

1998

Birth and Death: Doctor Control vs. Patient Choice

Sylvia A. Law

Follow this and additional works at: <https://scholarship.law.umn.edu/mlr>



Part of the [Law Commons](#)

Recommended Citation

Law, Sylvia A., "Birth and Death: Doctor Control vs. Patient Choice" (1998). *Minnesota Law Review*. 2398.
<https://scholarship.law.umn.edu/mlr/2398>

This Article is brought to you for free and open access by the University of Minnesota Law School. It has been accepted for inclusion in Minnesota Law Review collection by an authorized administrator of the Scholarship Repository. For more information, please contact lenzx009@umn.edu.

Birth and Death: Doctor Control vs. Patient Choice

Sylvia A. Law*

INTRODUCTION

In 1997, a unanimous Supreme Court rejected several terminally ill patients' claims that criminal prohibitions against physician-assisted death violate the Constitution; however, five of the Justices asserted that terminally ill patients have a right to adequate pain medication.¹ Nonetheless, a significant portion of dying patients suffer from severe untreated, but treatable, pain.²

* Elizabeth K. Dollard Professor of Law, Medicine and Psychiatry, New York University School of Law. B.A., Antioch College; J.D., New York University. I am grateful for the help and insight of the following people: Jessica Tsai, NYU Law 1999, my research assistant; Leslie Jenkins, my assistant; and Elizabeth Evans, NYU Law Librarian. They tracked down materials and provided editorial and logistical help. Kathryn L. Tucker, lawyer for the plaintiffs in the right to physician-assisted death cases, Dr. David Orentlicher, and my son, Benjamin Ensminger-Law, provided support and helpful comments on an earlier draft.

1. *Washington v. Glucksberg*, 117 S. Ct. 2258 (1997). Several concurring opinions were filed in this case. Justice O'Connor asserted, "There is no dispute that dying patients in Washington and New York can obtain palliative care, even when doing so would hasten their deaths." *Id.* at 2303 (O'Connor, J., concurring). Justice Souter observed that the law "permits physicians to administer medication to patients in terminal conditions when the primary intent is to alleviate pain, even when the medication is so powerful as to hasten death and the patient chooses to receive it with that understanding." *Id.* at 2289 (Souter, J., concurring). Similarly, Justice Breyer asserted, "the laws of New York and Washington do not prohibit doctors from providing patients with drugs sufficient to control pain despite the risk that those drugs themselves will kill." *Id.* at 2311 (Breyer, J., concurring). Justice Stevens observed, "Allowing the individual, rather than the State, to make judgments [about treatment at the end of life] . . . gives proper recognition to the individual's interest in choosing a final chapter that accords with her life story, rather than one that demeans her values and poisons memories of her." *Id.* at 2308 (Stevens, J., concurring). He went on to remark, "Encouraging the development and ensuring the availability of adequate pain treatment is of utmost importance." *Id.*

2. See, e.g., The SUPPORT Principal Investigators, *A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand*

People concerned with the way that individuals meet death observe that the issue has emerged in the United States in the 1990s as the post-World War II generation—the baby boomers—confront the deaths of parents and contemporaries, and contemplate their own deaths.³ Informed observers suggest an analogy between the contemporary movement to improve treatment at the end of life and the movement over the last three decades to make childbirth more responsive to patients.⁴ The post-World War II generation, and particularly feminist women, have transformed medical care in childbirth and other reproductive health services, moving them from traditions of physician control to enhanced patient choice.

This Essay explores the analogy between patient control of birth and reproduction and patient control of death. What can the movement for patient-centered treatment at the end of life learn from the earlier movement for patient-centered birth and control of reproduction? Are birth and death so different that analogies are limited or irrelevant? Has there really been a transformative movement toward patient control of childbirth and other reproductive health services, or is this claim overstated?

The subject of patient control over reproduction is vast. This brief Essay focuses on three issues of control of reproduction and explores the lessons this recent history offers for patient control of death. The aspects of reproduction addressed are childbirth, sterilization, and the education of physicians to perform abortions.

I. CHILDBIRTH

In the first half of the twentieth century, the portion of American babies born in the hospital increased from 10% to

Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), 274 JAMA 1591, 1595-97 (1995); see also COMMITTEE ON CARE AT THE END OF LIFE, INSTITUTE OF MEDICINE, APPROACHING DEATH: IMPROVING CARE AT THE END OF LIFE 2, 5-6, 57-58, 126-43, 237-40, 355-56 (Marilyn J. Field & Christine K. Cassel eds., 1997) [hereinafter INSTITUTE OF MEDICINE REPORT]; NEW YORK STATE TASK FORCE ON LIFE AND THE LAW, WHEN DEATH IS SOUGHT: ASSISTED SUICIDE AND EUTHANASIA IN THE MEDICAL CONTEXT 43-47 (1994); MARILYN WEBB, THE GOOD DEATH: THE NEW AMERICAN SEARCH TO RESHAPE THE END OF LIFE 19, 81-125 (1997); Charles S. Cleeland et al., *Pain and Its Treatment in Outpatients with Metastatic Cancer*, 330 NEW ENG. J. MED. 592, 594-95 (1994); Kathleen M. Foley, *The Treatment of Cancer Pain*, 313 NEW ENG. J. MED. 84, 87 (1985).

3. See INSTITUTE OF MEDICINE REPORT, *supra* note 2, at 3.

4. See WEBB, *supra* note 2, at 4, 224, 405.

90%.⁵ At the beginning of the century, women gave birth at home, attended by a midwife, family members, and neighbors. Childbirth was often dangerous and painful.⁶ Both women and physicians supported the movement to give birth in hospitals, under medical supervision.⁷ As childbirth moved to the hospital, the standard doctor-controlled operating procedures required that the woman be sedated through labor, the baby be removed from the unconscious mother by forceps, an incision (an episiotomy) be made to facilitate use of the forceps, and the placenta be removed by injecting a drug (ergot).⁸ Because the anesthetized woman might thrash about and injure herself, her arms and legs had to be restrained.

In the late 1960s and 1970s, as the post-World War II generation began to have babies, they challenged these common childbirth practices. Their claims, like those of the contemporary movement for compassion in dying, rested on two grounds. First, many aspects of the physician-controlled childbirth process were injurious to women and babies. Second, the standard operating procedures failed to acknowledge that birth is a social and spiritual experience, as well as a medical event.

In the 1990s, childbirth in the United States is dramatically different than it was in the 1960s. Childbirth preparation classes have become common. In some communities, women can choose to give birth with the help of a midwife, either at home or at a birthing center.⁹ While most women give birth in the hospital, that experience has also been transformed. In most hospitals, for most births, women are free to accept or reject

5. See JUDITH WALZER LEAVITT, *BROUGHT TO BED: CHILDBEARING IN AMERICA, 1730-1950*, at 12 (1986).

6. See *id.* at 13-35.

7. See *id.* at 196-212.

8. For an early, influential article presaging the increased medical regimentation of childbirth, see Dr. Joseph B. DeLee, *The Prophylactic Forceps Operation*, 1 AM. J. OBSTETRICS & GYNECOLOGY 34, 34-35 (1920). This trend continued throughout the 1950s and 1960s. "[O]perations research techniques used to expedite the manufacture of various forms of weaponry in WW II were applied to developing more effective obstetrical suites. . . . Priorities were formulated to facilitate the efficient processing of as many women as possible rather than to allow for an adjustable tempo for each individual birth." Roslynn Lindheim, *Birthing Centers and Hospices: Reclaiming Birth and Death*, 2 AM. REV. PUB. HEALTH 1 (1981).

9. See Debra Evenson, *Midwives: Survival of an Ancient Profession*, 7 WOMEN'S RTS. L. REP. 313, 325 (1983); Kathleen M. Whitby, Comment, *Choice in Childbirth: Parents, Lay Midwives, and Statutory Regulation*, 30 ST. LOUIS U. L.J. 985, 1000 & n.96 (1986).

pain relief, shaving, enemas, drugs to speed delivery, and other invasive procedures.¹⁰ Partners and friends can stay with the woman through labor and delivery. The woman can decide whether to keep her baby with her after birth or to have him or her cared for by others.¹¹

How did this change occur, and what lessons does it offer for the contemporary movement for a patient-controlled death? Some earlier proponents of patient-controlled birth initially looked to the courts, the Constitution, and the law for help. In *Fitzgerald v. Porter Memorial Hospital*,¹² several married couples who had prepared for childbirth by the LaMaze method challenged a public hospital policy that barred fathers from the delivery room, even though their own doctors supported their claims. They asserted that the hospital policy denied them a basic human choice that should be protected by the Constitution, and there was no medical justification for prohibiting the fathers' presence and help. The Seventh Circuit Court of Appeals, in an opinion authored by now Supreme Court Justice Stevens, rejected their constitutional claim. Overall, the law has played little role in the transformation of childbirth practices over the past thirty years, and constitutional law has played no role.¹³

Two factors were most important in transforming childbirth in America between the 1960s and the 1990s. First, women became informed and assertive. Second, the hospital and physician markets responded to women's concerns.

The process by which women became more informed and assertive in relation to childbirth was multifaceted and com-

10. See Keith P. Russell, *The Course and Conduct of Normal Labor and Delivery*, in CURRENT OBSTETRIC & GYNECOLOGICAL DIAGNOSIS & TREATMENT 681, 690, 704 (Ralph C. Benson ed., 5th ed. 1984) (identifying preparations that "should" be carried out prior to delivery).

11. See Beverly L. Koops & Randall B. Wilkening, *The Newborn Infant*, in CURRENT OBSTETRIC & GYNECOLOGICAL DIAGNOSIS & TREATMENT, supra note 10, at 790, 804-06.

12. 523 F.2d 716 (7th Cir. 1975).

13. In a few states, beginning with *Canterbury v. Spence*, 464 F.2d 772 (D.C. Cir. 1972), courts and legislators adopted a standard of informed consent that focused on the information patients needed to make informed treatment decisions, rather than on the professional customs of physicians. However, the changes in the physician-patient relation are much broader than anything required by a change in the law, and extend to states where the law has not changed. See JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* 65-71 (1984); SYLVIA A. LAW & STEVE POLAN, *PAIN AND PROFIT: THE POLITICS OF MALPRACTICE* 108-14 (1978).

plex. One important development was the publication of *Our Bodies, Ourselves*. Authored by the Boston Women's Health Collective, the book was first published in 1969, on newspaper stock, without any claim to copyright. New editions were published in 1973, 1984, and 1992.¹⁴ The book was the product of a movement concerned with the whole range of issues that affect women's health. By 1997, the book had sold over four million copies in fifteen languages.¹⁵ The book, "branded and banned as radical early on, has become mainstream."¹⁶

The book remains popular because it taps into historical and social movements and responds to a broad range of concerns of women in many different circumstances. For example, in relation to childbirth, it offers both social history and concrete medical, technical information. It supports women who choose home birth and advises those who give birth in high-tech teaching hospitals about what to expect and how to maximize patient control. It helps women to engage in dialogue with doctors and to select doctors and hospitals on a more informed basis. The movement toward informed, woman-controlled childbirth is dominated by educated middle-class women. But the changes in hospital and physician practices that it has generated have cut across class lines, at least to some degree.¹⁷

Informed patients, concerned about exercising control over their childbirth experience, found a market eager to meet their needs. Delivering babies for healthy, insured women is financially attractive to doctors and hospitals.¹⁸

How does this experience in the transformation of childbirth illuminate the current effort to transform the choices confronting dying patients? People confronting death have no resource comparable to *Our Bodies, Ourselves*. Derek Humphrey's

14. See BOSTON WOMEN'S HEALTH BOOK COLLECTIVE, *THE NEW OUR BODIES, OURSELVES: A BOOK BY AND FOR WOMEN* (25th anniversary ed. 1992) [hereinafter *OUR BODIES, OURSELVES*].

15. See Sara Rimer, *They Talked and Talked, and Then Wrote a Classic*, N.Y. TIMES, June 22, 1997, at 27.

16. *Id.*

17. See LEAVITT, *supra* note 5, at 213-18.

18. See Elisabeth R. Sullivan, *Hospitals Wooing Parents-to-Be: New Services, Facilities Offered to Obtain Lifetime Affiliations*, PHILADELPHIA INQUIRER, July 6, 1988, at B1. Indeed even when women are insured through Medicaid, hospitals compete fiercely to deliver their babies. See Tamar Lewin, *Hospitals Serving the Poor Struggle to Retain Patients: Private Centers Lure Away Medicaid Recipients*, N.Y. TIMES, Sept. 3, 1997, at A1.

best selling how-to book, *Final Exit*, addresses one important issue, suicide.¹⁹ Marilyn Webb's magnificent book, *The Good Death*, provides a powerful description of recent developments in relation to death. A growing number of works address particular aspects of pain and dying.²⁰ Support groups for people confronting particular illnesses proliferate.²¹

But there is no resource book on death, similar to *Our Bodies, Ourselves*. There is no book on dying that reflects a social movement, responds to changing circumstances, recognizes that the core issue is one of patient choice and respects the fact that people have divergent values. A comparable book about death and dying would be tremendously useful.

Even if the social movement of people concerned about death could generate a community of concern that could support a resource comparable to *Our Bodies, Ourselves*, it is not clear that the two situations, birth and death, are comparable. Childbirth provides a unique opportunity for planned patient choice. Many people plan their pregnancies. The nine months of gestation provide a neatly defined time for education, shopping, and choice. The birth of a child is often a desired, joyous experience. Ordinary people can make choices about birth precisely because it is, in most cases, a largely predictable and "healthy" process. By contrast, death, even if it is experienced as well as possible, is a profound loss. Death is messier, less predictable, and more complex than birth. It is not clear that people concerned about death constitute a social movement and community that is comparable to that supporting *Our Bodies, Ourselves*.²²

19. See DEREK HUMPHREY, *FINAL EXIT* (1991). The book, written by the founder of the Hemlock Society, provides detailed information about how to commit suicide. Within a week it rose to the top of the New York Times best seller list for how-to books. Humphrey commented that the success of the book "legitimized everything by making money." Andrew Solomon, *A Death of One's Own*, NEW YORKER, May 22, 1995, at 54, 59.

20. See, e.g., DAVID B. MORRIS, *THE CULTURE OF PAIN* (1991) (discussing the process of death with special concern for pain); SHERWIN NULAND, *HOW WE DIE* (1994) (describing and attempting to de-mythologize the process of dying); ELISABETH KÜBLER-ROSS, *ON DEATH AND DYING* (1969) (discussing the emotional aspects of death); PATRICIA WEENOLSEN, *THE ART OF DYING* (1996) (same).

21. See WEBB, *supra* note 2, at 206-07.

22. The movement concerned with death does, however, command financial and professional resources that have never been available to the movement for women-centered childbirth. See *id.* at 339-400.

Further, it is not clear that the market will be as responsive to the needs of dying people as it has been to the needs of women giving birth. Childbirth is cheap, especially when all goes well.²³ Death is expensive, particularly when well-supported.²⁴ Thus, many reasons suggest that it will be difficult to use the movement toward patient-controlled childbirth as a helpful model for patient-controlled death.

Further, patient-controlled childbirth, far from being a model, is rare. Most pregnant women must choose between access to technology and control of birth. A few programs in a few cities offer women control of the birth process, with easy access to high-tech services if they become necessary.²⁵ But most women must choose. If a woman chooses home birth or hospital birth in a small local community, she will not have easy access to technology if problems develop.²⁶ If, on the other hand, she chooses to give birth at a high-tech hospital she will be required to accept the current version of standard operating procedures.²⁷

Similar choices confront dying people. Hospice is the death equivalent of home birth. Hospice programs help patients to control pain and physical symptoms and to address personal and spiritual aspects of death. But to enter most hospice programs the patient, and his or her physician, must forsake efforts at cure.²⁸ Medicare will fund hospice care only if

23. See OUR BODIES, OURSELVES, *supra* note 14, at 435-40.

24. See WEBB, *supra* note 2, at 209; see also *infra* notes 28-30 and accompanying text (discussing the costs of hospice care).

25. See, e.g., BARBARA BRENNAN & JOAN R. HEILMAN, *THE COMPLETE BOOK OF MIDWIFERY* 14-15, 50-51 (1977).

26. Dr. David Hilfiker describes a "wonderfully normal" childbirth gone wrong in a small hospital without resources. See DAVID HILFIKER, *HEALING THE WOUNDS* 45-47 (1985).

27. See generally David Banta & Stephen B. Thacker, *The Risks and Benefits of Episiotomy: A Review*, 9 BIRTH 25, 29 (1982) (noting that episiotomies are routinely required even though evidence does not support their benefit); David A. Luthy et al., *A Randomized Trial of Electronic Fetal Monitoring in Preterm Labor*, in 69 OBSTETRICS & GYNECOLOGY 687, 694 (1987) (noting that even though electronic fetal monitoring is routinely required, studies have not demonstrated any benefit from the procedure); Kirkwood K. Shy et al., *Effects of Electronic Fetal Heart Rate Monitoring, Compared with Periodic Auscultation, on the Neurologic Development of Premature Infants*, 322 NEW ENG. J. MED. 588, 591 (1990) (finding that electronic fetal monitoring does not produce benefits, at least with regard to mitigation of neurological disorders, even though it is commonly required).

28. See Joanne Lynn et al., *Defining the "Terminally Ill": Insights from SUPPORT*, 35 DUQ. L. REV. 311, 312 (1996) (noting that only 15% of patients

a physician certifies that a patient is likely to die within six months.²⁹ Additionally, to qualify for most hospice care programs, a dying individual must have another person willing to serve as his or her primary caretaker, a home in which he or she can die peacefully, and an environment that is sufficiently stable into which to bring opiate drugs.³⁰

Rational, professional, and financial considerations support policies that require people to make these choices in relation to birth and death. In relation to birth, medical professionals honestly believe that a closely monitored birth in a technically sophisticated setting is better for mothers and infants.³¹ Because they believe this, responsible doctors and hospitals are reluctant to support alternative forms of childbirth.

In relation to death, the reasons for requiring people to choose between hospice care and curative treatment are somewhat different. A central element of the hospice care philosophy is an acceptance of the fact that a person is dying.³² Further, most hospice care involves nontechnological caring services. The United States is extremely reluctant to fund nontechnological caring services.³³ Vulnerable people—infants, the dying, people with disabilities—have significant needs for caring help. Those needs have traditionally been met by families, without compensation.³⁴

receiving hospice care are alive after six months and the median survival in hospice care is only thirty-six days).

29. See 42 U.S.C. § 1395x(dd) (West Supp. 1997); INSTITUTE OF MEDICINE REPORT, *supra* note 2, at 30, 168-69.

30. See INSTITUTE OF MEDICINE REPORT, *supra* note 2, at 31; WEBB, *supra* note 2, at 213.

31. The American College of Obstetricians and Gynecologists considers home birth tantamount to child abuse; some hospitals will withdraw staff privileges from doctors who help women to give birth at home. See George J. Annas, *Home Birth: Autonomy v. Safety*, HASTINGS CENTER REP., Aug. 1978, at 19, 19.

32. See INSTITUTE OF MEDICINE REPORT, *supra* note 2, at 102-05.

33. For example, Medicare covers home health care services only if they are needed on an intermittent or part-time basis, provided under the direction of a physician. See 42 C.F.R. § 409.40 (1997). Housekeeping and transportation services are not covered. See *id.* § 409.41. The costs of Medicare's home health care benefit has grown rapidly in the 1990s. See INSTITUTE OF MEDICINE REPORT, *supra* note 2, at 171-72.

34. More precisely, these caring needs have been met by the unpaid work of women in the home. See Chai R. Feldblum, *Home Health Care for the Elderly: Programs, Problems, and Potentials*, 22 HARV. J. ON LEGIS. 193 (1985); Sylvia A. Law, *Equality: The Power and Limits of the Law*, 95 YALE L.J. 1769, 1780-86 (1986) (discussing political perspectives on the care of the frail elderly).

Thus, hospice follows a strong American tradition. Ordinary needs should be met by families. The community should assure access to extraordinary needs for life-saving medical care.³⁵ But the line between serious medical care and support for the activities of daily living must be seriously policed.

Forcing patients to choose between technology and cure, on the one hand, or patient-centered comfort care, on the other, is not inevitable or wise for either birth or death. It is possible to have both. But we have a deep cultural tradition, in relation to both birth and death, of forcing people to choose.

II. STERILIZATION

Recent decades have seen a similar movement from doctor control to patient choice in relation to sterilization. For most of the twentieth century in the United States, sterilization was completely controlled by doctors and the state. For some people—criminals, the retarded, and the poor—sterilization was required.³⁶ For others, sterilization was prohibited. Until the

35. See, e.g., The Emergency Medical Treatment and Active Labor Act of 1986, 42 U.S.C. § 1395dd (1994). The Act requires all hospitals to provide emergency care and treatment for women in active labor. See *id.* § 1395dd(e); cf. *Power v. Arlington Hosp.*, 42 F.3d 851, 856 (4th Cir. 1994) (observing that Congress enacted this statute to respond to incidents of "patient dumping" when hospitals would refuse to treat patients who could not pay or would transfer them before their conditions had stabilized).

36. See *Buck v. Bell*, 274 U.S. 200, 207 (1927) (approving state-mandated sterilization of a woman alleged to be retarded). Ironically, the woman at the center of this historic case, Carrie Buck, was not retarded. See Paul H. Lombardo, *Three Generations, No Imbeciles: New Light on Buck v. Bell*, 60 N.Y.U. L. REV. 30, 52 (1985). Reflection on the Nazi experience in World War II ultimately made state-mandated sterilization socially unacceptable. See, e.g., *Skinner v. Oklahoma*, 316 U.S. 535, 541-43 (1942) (striking down a state program that required sterilization of recidivist criminals except those convicted of white-collar crimes).

In recent decades sterilization has been required by doctors, rather than the state. See, e.g., *Walker v. Pierce*, 560 F.2d 609 (4th Cir. 1977), *cert. denied*, 434 U.S. 1075 (1978). Dr. Pierce, an obstetrician practicing in a small community, refused to deliver babies for poor women who had two children unless they "agreed" to be sterilized. *Id.* at 611. The court found "no reason why Dr. Pierce could not establish and pursue the policy he has publicly and freely announced." *Id.* at 613.

Unlike some of his colleagues, Dr. Pierce announced his policy in advance. More common is the practice of asking women to consent to sterilization during labor. See *Relf v. Weinberger*, 372 F. Supp. 1196, 1199 (D.D.C. 1974), *vacated*, 565 F.2d 722 (D.C. Cir. 1977). In response to this suit, federal regulations require informed consent that must be obtained if a sterilization is to be financed by Medicaid. These regulations mandate a 72-hour waiting period between the time of consent and the operation and prohibit sterilization of

1970s, professional organizations and hospital policies enforced "The Rule of 120" that prohibited sterilization unless the patient's age, multiplied by her number of living children, equaled 120.³⁷

By the 1990s, legal and professional attitudes toward sterilization had been transformed. Now, sterilization is perceived as a matter of patient choice, rather than professional or state control. The Rule of 120 has been abandoned and sterilization has become the most common form of contraception in the United States.³⁸ Mandated sterilization is no longer socially or legally acceptable.³⁹

As a formal matter, in the past three decades, legal and professional attitudes toward sterilization have changed from an assumption of doctor control to one of patient choice. Despite this change in the formal norms, it may well be the case that women, particularly poor women and women of color, are still sterilized without true consent.⁴⁰ In the late 1970s, when Ralph Nader and various women's health organizations monitored

women under age 21. *See Voe v. Califano*, 434 F. Supp. 1058 (D. Conn. 1977) (upholding the constitutionality of the minors provision); 42 C.F.R. §§ 50.201-50.206 (1997).

37. *See* William D. Mosher & Christine A. Bachrach, *Understanding U.S. Fertility: Continuity and Change in the National Survey of Family Growth, 1988-1995*, 28 FAM. PLAN. PERSP. 4, 6 (1996).

38. *See id.*

39. *See supra* note 36 and accompanying text; *see also In re Lacey P.*, 433 S.E.2d 518 (W. Va. 1993). The trial court ordered a mother, whose parental rights had been terminated because she neglected her children, to be sterilized. *See id.* at 521. The West Virginia Supreme Court held that the case was moot because the mother had Norplant implanted. *See id.* at 524. The state supreme court implied in dicta that the original holding would have been invalid. *See id.* at 525.

Later disputes about mandatory sterilization have often involved retarded people. Many states authorize sterilization of sexually active retarded people. *See, e.g.,* North Carolina Ass'n for Retarded Children v. North Carolina, 420 F. Supp. 451 (M.D.N.C. 1976). Some states allow retarded people to be sterilized if sterilization would be in the patient's best interest and the patient can provide some form of informed consent. *See, e.g., In re Guardianship of Hays*, 608 P.2d 635 (Wash. 1980). Yet other judges are skeptical whether sterilization is ever appropriate for retarded people. *See, e.g., In re Valerie N.*, 707 P.2d 760, 782 (Cal. 1985) (Bird, C.J., dissenting).

40. Sterilization is the most commonly used form of contraception in the United States. *See Mosher & Bachrach, supra* note 37, at 6. Low-income women, those with little education, and Hispanics and blacks are most likely to be sterilized. *See* THOMAS M. SHAPIRO, *POPULATION CONTROL POLITICS: WOMEN, STERILIZATION AND REPRODUCTIVE CHOICE* 134 (1985); *see also* Dorothy E. Roberts, *Punishing Drug Addicts Who Have Babies: Women of Color, Equality, and the Right of Privacy*, 104 HARV. L. REV. 1419, 1442-43 (1993).

compliance with sterilization consent requirements, they found that violations were common.⁴¹ In the 1990s, few public or private organizations monitor for sterilization abuse.

In the 1990s, access to pain-relief medication is similar to sterilization in the 1970s, in that doctors are in control. As with sterilization in the 1970s, doctor control raises two problems. First, many terminally ill patients are denied the pain relief that they want. Second, some patients may be provided "terminal sedation" even though they have not sought it.

Undertreatment of pain is probably the more serious problem.⁴² For example, doctors at Memorial Sloan-Kettering, perhaps the most advanced hospital center for the treatment of cancer and of dying patients in the United States, assert that, "[u]nder informed consent and medical self-determination, it is a patient's legal right to reject sedation for symptom control if it is offered but it is not something patients can demand from a doctor."⁴³ Patients can reject treatments, even if death is a certain consequence.⁴⁴ But they cannot demand pain control even if they are dying. The doctor is in charge.

Doctors and other health care professionals systematically undertreat pain.⁴⁵ Palliative care is not a recognized specialty in U.S. medical education, as it is in many European countries, and doctors are not routinely well trained in palliative care.⁴⁶ Effective treatment of pain is a necessary pre-condition to the dying patient's ability to deal with the personal and spiritual aspects of death.⁴⁷

The law reinforces physicians' professional inclinations to undertreat pain. When doctors prescribe narcotics, often the most effective pain medication, they must fill out special triplicate forms and submit a copy to the state. The triplicate form requirements have a significant impact discouraging doctors from prescribing sufficient drugs to control the pain of terminally ill

41. See Sylvia A. Law, *Sterilization Comes Easier for the Disadvantaged*, 23 N.Y.U. L. CENTER BULL. 15, 17 (1977).

42. See studies cited *supra* note 2.

43. WEBB, *supra* note 2, at 119.

44. See, e.g., *Lane v. Candura*, 376 N.E.2d 1232, 1233 (Mass. App. Ct. 1978).

45. See INSTITUTE OF MEDICINE REPORT, *supra* note 2, at 131-32.

46. See *id.* at 113, 209, 212, 216, 218-27, 328-31, 338-53; WEBB, *supra* note 2, at 77, 88.

47. See WEBB, *supra* note 2, at 227.

people.⁴⁸ In 1977, a unanimous Supreme Court rejected an argument that New York's version of this law violated the privacy rights of patients who feared that the information might become public.⁴⁹ The claim presented was an extremely broad and abstract challenge to the constitutionality of the statute on its face. Plaintiffs presented no evidence of any risk that confidential information would be improperly revealed.⁵⁰ The state, by contrast, presented strong evidence of diligence in preserving the confidentiality of the information contained in the forms.⁵¹ Plaintiffs did not allege, and the Court did not consider, any claim that the triplicate form requirement would prevent patients from receiving medication for pain. In light of the Supreme Court's 1997 assumption that patients have a right to pain medication, and the overwhelming evidence that the triplicate form requirement deters doctors from providing necessary pain relief, the constitutionality of the triplicate form requirement should be challenged, and the Court should recognize that it imposes an unconstitutional burden on access to care at the end of life.

State medical boards investigate and discipline doctors who overprescribe pain medication.⁵² For example, in 1987, Dr. Ronald Blum, a Professor of Oncology at NYU Medical School and Deputy Director of the Kaplan Cancer Center, was working with doctors from Memorial Sloan-Kettering on a clinical trial of a new form of pain medication. Officials from the State Health Department came to his office, flashed badges and guns, and gave him Miranda warnings. He was charged with the criminal offense of failing to retain all of his triplicate form records for the preceding five years and failing to report some of his terminally ill cancer patients as habitual drug users or addicts. Dr. Blum hired a criminal defense lawyer and the case was eventually dismissed.⁵³ No doctor is ever disciplined for failure to treat pain.⁵⁴ Under federal law it is a crime for

48. See WEBB, *supra* note 2, at 227.

49. See *Whalen v. Roe*, 429 U.S. 589, 600 (1977).

50. See *id.* at 601.

51. See *id.* at 602.

52. See INSTITUTE OF MEDICINE REPORT, *supra* note 2, at 194-95 (citing David E. Joranson, *State Medical Board Guidelines for Treatment of Intractable Pain*, AM. PAIN SOC'Y BULL., May/June 1995, at 1).

53. See WEBB, *supra* note 2, at 92-93.

54. One case, *Estate of Henry James v. Hillhaven Corp.*, Super Ct. Div. 89CVS 64 (Hertford Cty., N.C. Nov. 20, 1990), held a nursing home liable for failing to administer the pain medication that the physician had ordered.

anyone other than a doctor to sell a Schedule II drug, which includes most effective forms of pain relief.⁵⁵ Pharmacists face incentives similar to those that confront doctors. To avoid risks of professional discipline and criminal prosecution, many pharmacists simply do not stock narcotic pain medications.⁵⁶

Both physician attitudes and the law make it particularly difficult for people who have used narcotic drugs to obtain adequate pain relief. The common assumption is that if a person has a history of using illegal drugs for recreational purposes, he or she is not entitled to pain relief when terminally ill.⁵⁷ Even if we accept the legitimacy of public policy that makes some drugs illegal for recreational purposes, and recognize the difficulty of enforcing this public policy, it seems cruel to deny pain relief to terminally ill patients on that basis.

While undertreatment of pain is the most serious problem confronting terminally ill patients, as with sterilization, there may also be a problem in relation to doctors who provide terminal sedation to patients who would choose to endure pain and struggle to live. In 1988, the *Journal of the American Medical Association* published an anonymous article by a gynecological resident in which he described giving a lethal injection to a twenty-year-old woman named Debbie, who was dying of ovarian cancer.⁵⁸ He was called to her bedside in the middle of

However, that is quite different from holding a doctor liable for failing to prescribe adequate pain medication. Ordinary malpractice standards require a plaintiff to show that a doctor's failure to conform to professional standards caused injury. Given that common professional standards systematically undertreat pain in terminally ill patients, it is difficult to establish that doctors who undertreat have violated professional standards. See *supra* note 2 and accompanying text (noting that many patients suffer from untreated pain). See generally Kathryn L. Tucker, *Surrogate End of Life Decisionmaking: The Importance of Providing Procedural Due Process, A Case Review*, 72 WASH. L. REV. 859 (1997) (exploring a doctor's professional duty to treat pain).

55. See 21 U.S.C. § 812(b)(2) (1994) (definition); *id.* §§ 829(a), 841(a) (criminal prohibitions). Under federal law, Schedule I drugs are deemed so dangerous and inappropriate that it is crime to use or sell them even for medical purposes, under physician supervision. Schedule I drugs include heroin, LSD and marijuana. In 1996, Arizona and California approved the medical use of marijuana. It appears that these state initiatives violate federal law. Federal officials recognize that the most likely means of enforcing the federal ban against medical marijuana is discipline of physicians by state medical boards. See *Prescription for Addiction? The Arizona and California Medical Drug Use Initiatives: Hearing Before the Comm. on the Judiciary of the U.S. Senate*, 104th Cong. 71 (1996).

56. See WEBB, *supra* note 2, at 19, 98.

57. See INSTITUTE OF MEDICINE REPORT, *supra* note 2, at 195-96.

58. See Anonymous, *It's Over, Debbie*, 259 JAMA 272 (1988).

the night because she was in great pain.⁵⁹ He had never before met the patient.⁶⁰ She said, "Let's get this over with."⁶¹ The resident administered a lethal injection.⁶² The *Journal* received over 150 letters in response to the column.⁶³ Approximately 80% of the respondents opposed the actions of the physician and 75% believed that the *Journal* should not have published the piece.⁶⁴ The concerns expressed in the letters included the fact that the doctor did not know the patient, the patient may not have felt the same way the next morning, and the doctor had not done all that was possible to deal with her symptoms.⁶⁵

The Supreme Court's 1997 decision, affirming patients' right to pain treatment at the end of life, pays little attention to the issue of patient consent and control. The plaintiffs, who challenged criminal prohibitions against physician-assisted suicide, gave careful, conservative attention to the matter of patient choice. Compassion in Dying has developed a complex process to assure authentic, informed, voluntary patient choice. Kathryn L. Tucker, the principal lawyer representing the dying patients who sought physician help in dying, has also represented patients who resisted doctor and hospital efforts to terminate life support.⁶⁶ The Supreme Court's easy assumption that pain relief is available⁶⁷ is empirically wrong.⁶⁸ Further, it wholly fails to address the problems of protecting patient choice.⁶⁹

59. See *id.* at 272.

60. See *id.*

61. *Id.*

62. See *id.*

63. See George D. Lundberg, "It's Over, Debbie" and the Euthanasia Debate, 259 JAMA 2142, 2142 (1988).

64. See *id.*

65. See, e.g., Letters, "It's Over, Debbie", 259 JAMA 2094-98 (1988).

66. See Tucker, *supra* note 54, at 861. Physicians sought to withdraw treatment without first learning the patient's wishes. Even though the patient's ability to communicate was limited, had the doctors sought his views, they would have learned that he wished to continue treatment. See *id.* The doctors' decision to withdraw treatment was reversed by the aggressive action of the patient's former wife, who obtained a court order to resume life support. See *id.*

67. See *supra* note 1 (discussing pain relief options available to patients in Washington and New York).

68. See *supra* note 2 and accompanying text (examining the reality of pain relief options available to dying patients).

69. See David Orentlicher, *The Supreme Court and Physician-Assisted Suicide: Rejecting Assisted Suicide but Embracing Euthanasia*, 337 NEW ENG. J. MED. 1236, 1238 (1997).

In short, the movement for a patient-controlled death has much to learn from the movement from doctor control to patient choice in relation to sterilization. Both professional standards and the law can make a difference. Medical licensing boards, for both physicians and pharmacists, could do much to assure doctors that they will not be disciplined for providing adequate pain medication for terminally ill patients. Indeed, these boards could take a leadership role in imposing sanctions on doctors and pharmacists who make it unreasonably difficult for terminally ill patients to obtain pain relief. At the same time, professional ethics and medical education should do more to make plain to doctors that terminally ill patients retain, to the extent possible, the right to reject terminal sedation. At the same time, our experience in relation to both childbirth and sterilization suggests that changes in the law, while sometimes necessary, are not sufficient to modify traditional physician attitudes and established patterns of patient-physician relationships. In addition, a move toward greater patient control requires that patients be educated and supported in seeking greater control of their bodies and lives.

III. MEDICAL EDUCATION, PAIN AND ABORTION

A growing consensus recognizes that medical education fails to train doctors to provide competent care to dying patients.⁷⁰ "Deficiencies in undergraduate, graduate, and continuing education for end-of-life care reflect a medical culture that defines death as failure and ignores care for dying people as a source of professional accomplishment and personal meaning."⁷¹

Medical education has similarly failed to train doctors to perform abortions. Even though abortion is the most common surgical procedure in the United States,⁷² in 84% of the counties in the United States no doctor openly provides them.⁷³ Medical schools do not train doctors to perform abortions; indeed, 47% of residents specializing in obstetrics and gynecology reported that at the end of four years of specialized training they

70. See INSTITUTE OF MEDICINE REPORT, *supra* note 2, at 207-34; WEBB, *supra* note 2, at 42-48.

71. INSTITUTE OF MEDICINE REPORT, *supra* note 2, at 207.

72. See FREDERICK S. JAFFE ET AL., ABORTION POLITICS: PRIVATE MORALITY AND PUBLIC POLICY 7 (1981).

73. See Stanley K. Henshaw & Jennifer Van Vort, *Abortion Services in the United States, 1991 and 1992*, 26 FAM. PLAN. PERSP. 100, 100 (1994).

had acquired *no* experience in performing first trimester abortions.⁷⁴ In 1993, medical students, concerned about this failure, organized to encourage their schools and training programs to provide education on abortion.⁷⁵ In 1995, the Accreditation Council for Graduate Medical Education (ACGME) promulgated standards requiring that medical education programs provide training in abortion. Programs that oppose abortion on moral or religious grounds could meet the obligations by arranging training at another institution for students who do not share those religious concerns. In response to strong political opposition, the standards were substantially relaxed during 1995. The impact of this new policy remains to be seen.⁷⁶

Many of the same factors discourage medical education from providing adequate training to enable doctors to provide competent care to people who are dying and to people who seek abortions. In both cases, the services required are often low-tech and non-heroic. In both cases, there are significant strains of moral opposition to meeting patient needs. Insofar as medical education is based primarily in acute care hospitals, it is challenging to provide education for services that are typically provided on an outpatient basis.

On the other hand, several factors suggest that it might prove to be easier to transform medical education to train doctors to provide competent care for dying patients than to assure that doctors are trained to provide abortion. Most importantly, death comes to everyone, while abortions are needed only by sexually active women. Over the past few years, large amounts of private funds and professional resources have been invested to study and improve the care of dying patients.⁷⁷ There has

74. See Carolyn Westhoff et al., *Residency Training in Contraception, Sterilization and Abortion*, 81 OBSTETRICS & GYNECOLOGY 311, 312 tbl.3 (1993). The proportion of obstetrics and gynecology residency programs providing routine training in first trimester abortions decreased from 23% in 1985 to 12% in 1992, and the proportion providing routine training in second trimester abortions declined from 21% to 7%. See H. Trent MacKay & Andrea P. MacKay, *Abortion Training in Obstetrics and Gynecology Residency Programs in the United States, 1991-1992*, 27 FAM. PLAN. PERSP. 112, 112-14 & 113 tbl.1 (1995).

75. See Susan Gilbert, *Clinic Violence Sets Off Push for Wider Abortion Training*, N.Y. TIMES, Jan. 11, 1995, at C11.

76. The various versions of the ACGME policy on abortion training are set forth in RAND E. ROSENBLATT ET AL., LAW AND THE AMERICAN HEALTH CARE SYSTEM 1325-26 (1997).

77. See The SUPPORT Principal Investigators, *supra* note 2, at 1591; INSTITUTE OF MEDICINE REPORT, *supra* note 2, at 327-57; WEBB, *supra* note 2, at 399-400.

been no comparable investment of money or professional resources to encourage the education of doctors to provide abortions.

CONCLUSION

Perhaps the most important lesson that the movement toward patient-controlled reproduction has to offer those concerned about patient control of death is the importance of informed patient planning. Even though psychological and practical factors make planning for death much more difficult than planning for birth, much more could be done to provide dying patients and their families the information that they need to make informed choices and to act upon them.

Further, our experience in relation to sterilization for people who seek it suggests that changes in professional attitudes can have an important impact. So too in relation to patient-controlled death, changes in professional norms could be important. Our experience in relation to involuntary sterilization, by contrast, suggests that the law can have a major effect in changing formal state policy, but a more modest impact in affecting professional behavior.

Our experience in relation to medical education and abortion is perhaps most sobering. Even though a very broad consensus of the medical profession has recognized that there is a pressing need to do a better job to train doctors to provide abortions, and referrals for abortion, change has been very slow in coming. Abortion, of course, raises different moral and political issues than does patient-controlled death.

For almost three decades, millions of patients and physicians have grappled with the issues of patient control in the context of reproductive health services. While there have been great transformations, serious problems persist. As the culture now turns attention to these issues in the context of pain and death, we can learn much from this earlier experience. One core lesson of history is that change is slow and difficult.

